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Outcome Measurement And Service Evaluation – A Note on Research Design

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Summary

The purpose of this research note is to demonstrate how an individualised quality of life instrument could be adapted to provide a more accurate estimate of the impact of a social service on a person's quality of life. An increase in quality of life between the start and end of a service is often taken as an indication that the service impacted positively on quality of life. The modifications to the quality of life instrument suggested in this paper show that this assumption is not always accurate and should be questioned directly.

Research into the effectiveness of social services often unavoidably lacks a high degree of internal validity due to, for example, ethical, financial or operational concerns. Research designs in this area frequently take the form of cohort studies or before-and-after studies, where allocation of clients to the treatment group is not influenced by the fact that a research study is being conducted. The advantage of such designs is that they are high in external, and more specifically, ecological validity (phenomena are studied in their “natural” environment and therefore the research setting is low in artificiality). However, the disadvantage lies in the inability of such designs to provide accurate information about the effect of a service on an outcome of interest. Therefore, when using such research designs, it is incumbent on researchers to gather information that will enable the closest possible estimation of the nature of any cause and effect relationships between service and outcome.

This research note demonstrates how an instrument designed to measure individualised quality of life – the Patient Generated Index (Ruta *et al.*, 1994) – can be adapted to provide additional information about service effectiveness and the impact of services on quality of life. This can help social workers to build evidence to suggest that services for which they are responsible are effective (or not).

Quality of life is difficult to define because it is a subjective, dynamic concept (Alison *et al.*, 1997) based on an individual’s internal frame of reference or understanding and perceived life experience. Most existing questionnaire measures of quality of life consist of pre-determined items and domains which are pre-supposed to be equally important. Furthermore, the content and structure of these quality of life measures tend to be developed from the “top-down” by clinicians and academics. Outcome assessment needs to incorporate the unique perspective of each person on his or her own quality of life (O’Boyle, 1997). This phenomenological approach to the measurement of quality of life has received increasing attention among health care researchers and several measures of individual quality of life have been developed. One of the most commonly used individualised measures is the Patient Generated

Index (PGI). The PGI has been used successfully for people with obstructive sleep apnoea – people who temporarily stop breathing during sleep (Jenkinson *et al.*, 1998), atopic dermatitis – people with a skin disorder due to an allergy (Herd *et al.*, 1997) and back pain (Ruta *et al.*, 1994).

The original PGI consists of three stages. Stage 1 asks people to identify up to five areas of their life which are important to them and have been affected by their medical condition. Stage 2 allows people to score each of these areas and a sixth area entitled “all other aspects of your life not mentioned” from 0 (“the worst you could imagine”) to 100 (“exactly as you would like to be”) to reflect the extent to which their illness has had an impact on their lives. At stage 3, the respondents are asked to imagine that they have 60 points which can be used to improve the six life areas. The respondents “weight” the relative importance of each life area by allocating points. We allowed people to spend a total of 100 points at stage 3, because this was found to be easier to comprehend in an earlier pilot study.

A total quality of life score for each individual can be calculated:

$$\text{Total quality of life score} = _ (\text{Stage 2} * (\text{Stage 3} / 100))$$

In other words, for each life area, we take the score obtained by the individual at stage 3 and divide this by 100. We then multiply the result with the score obtained at stage 2. This will provide a single score for each life area (including the sixth area “all other aspects”). Finally, we sum these scores for each of the six life areas and the answer is the individual’s total quality of life score. This results in a possible range of scores from 0 to 100, with a higher score indicating a higher quality of life.

In order to add a specific service evaluation dimension to the PGI, a further stage (stage 4) was developed and appended. At stage 4, participants were asked to quantify the impact (positive or negative) that the service had had on each life area, by choosing one of six possible responses: “none”, “not very much”, “only a little”, “some”, “quite a lot” and “a great deal”. These responses were scored from 0 to 5 respectively and were given a positive or negative sign depending on the nature of the

impact indicated by respondents. This procedure provided an indication of the degree to which the service affected each area of life. It also allowed the extent to which the service impacted on the individual's total quality of life to be calculated:

$$\text{Impact index} = \frac{1}{100} \left(\left(\frac{\text{Stage 3}}{100} \right) * \left(\frac{\text{Stage 4}}{5} \right) \right)$$

In other words, for each of the six life areas, we take the score obtained at stage 3 and divide this by 100. Then take the score obtained at stage 4 and divide this by 5. We then multiply the two answers, which provides a single score for each life area. Finally, we sum the results obtained for each of the six life areas and the answer is the impact index. The impact index can range from 0 to 1.

Method

As part of an evaluation of an early hospital discharge scheme, stages 1 to 3 of the adapted PGI were completed by 12 adults (mean (SD) age = 76.5 (5.1) years) at entry to the scheme (discharge from hospital). Most had been admitted to hospital as a result of fractures. All four stages of the adapted PGI were completed by these respondents at discharge from the scheme. The median time spent on the scheme was 42 days.

The scheme provided intensive domiciliary care, with the aim of returning clients to the level of independence that they had attained before admission to hospital. Care was provided by several professional disciplines, but the service was co-ordinated and led by social workers who were, therefore, interested in the clients' perceptions of the impact of the service on their rehabilitation.

Results and Discussion

Analysis of the change in total quality of life scores, using the Wilcoxon Test, showed a significant increase in respondents' overall quality of life (median score at entry to scheme = 0; median score at exit from scheme = 25; $p = 0.02$). However, 7/12 respondents recorded an impact index of 0. In most cases where quality of life is used as an outcome measure, it is measured at the start and at the finish of an intervention. A statistically significant change in quality of life between these two points in time is accepted, usually, as evidence that the intervention is related to change in quality of life. However, using the procedure outlined above, the intervention was not perceived to affect quality of life by the majority of participants, even though the quality of life scores reported by participants showed a statistically significant increase. The lack of internal validity inherent in research designs such as the one described here does not allow implications about the effect of one variable (a service) on another (quality of life), but the introduction of an additional stage (described above) to the original PGI provides researchers and practitioners with a more accurate picture about the extent to which an intervention is perceived by the individual to affect his/her life quality. This method of calculating an "impact index" is easy to use with the PGI and provides a concise method of enabling social workers to measure the impact of an intervention on quality of life from an individual viewpoint. Further work is recommended to examine the standardisation and concurrent validity of this new stage.

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